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ABSTRACT

Michigan was the first state to apply the permanency planning philosophy to children in the mental health system who have developmental disabilities or severe emotional disorders. Permanency planning involves identifying strategies for supporting children within permanent family relationships. This report outlines how the permanency planning philosophy is being implemented in Michigan's developmental disabilities and mental health systems, through family reunification, foster care, shared parenting, and adoption. It describes services provided by community mental health boards and children's initiatives of the Department of Mental Health. The state's efforts to engage in interagency collaboration are also discussed, along with challenges presented by the cultural diversity within the state. The perspectives of biological, foster, and adoptive families on issues in permanency planning are explored. The report concludes that, while many problems and concerns were identified, the fact remains that children with disabilities in Michigan have a better chance than anywhere else in the U.S. of having a stable and permanent family to live in, and of having much of the support they need. (Contains 17 references.) (JDD)

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Center on Human Policy

PERMANENCY PLANNING IN MICHIGAN: FROM PHILOSOPHY TO REALITY

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PERMANENCY PLANNING IN MICHIGAN: FROM PHILOSOPHY TO REALITY

by

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FROM PHILOSOPHY TO REALITY

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Introduction

The State of Michigan stands alone in its commitment to permanency planning for children with severe emotional disorders and developmental disabilities (Taylor & Newman, 1993; Taylor, Racino, Walker, Lutfiyya, & Shoultz, 1992). While other states are beginning to endorse the philosophy of permanency planning for these children, Michigan has translated its philosophical commitment into policies, procedures, and concrete initiatives.

Early in the 1970s, the State of Michigan formed and acted upon a commitment to bring people with developmental disabilities out of institutions and into the community, and had, by the late 1970s, placed a large number of children out of state institutions and into group settings (group homes and pediatric nursing homes) and foster care. In October, 1982, with federal grant support, the Michigan Department of Mental Health initiated a Permanency Planning Project. This project was originally an effort to find adoptive homes for children, but it soon became a broad-based effort to ensure that every child with developmental disabilities had the opportunity to live with a permanent family rather than in a group or temporary family setting. Those involved in the Permanency Planning Project identified strategies for supporting children with

developmental disabilities within permanent family relationships, such as services and cash subsidies to maintain the child with the birth family, family reunification efforts, and placement of children in permanent foster or adoptive homes rather than in congregate settings.

Over the next few years, with initiatives such as the development of family support programs beginning in 1983, passage of a Family Support Subsidy bill late in 1983, and receipt of approval for a Medicaid waiver program for 50 children in 1986, the Department of Mental Health implemented its overall permanency planning philosophy.

The larger context for this change in outlook was the enactment by the United States Congress of Public Law 96-272, the Adoption Assistance and Child Welfare Law of 1980, and the efforts by child welfare systems across the country to comply with that law's permanency planning mandate for children in foster care and other out-of-home settings. Michigan was the first state to apply the permanency planning philosophy to children in the mental health system who have developmental disabilities. Fairly recently, they have extended that philosophy to children with severe emotional disorders as well.

The Michigan Service System

For services funded by the Department of Mental Health, the state has moved toward a "full management" system, in which community mental health boards which operate within one or more counties provide (with a combination of federal, state, and

local funding) mental health and developmental disability services to children and adults. There are still state-operated programs, but the full management counties pay full cost for their residents served by those programs. The renowned Macomb-Oakland Regional Center is the only state-operated community program left in Michigan, and the two counties in which it operates can either contract with Macomb-Oakland or with other agencies for the services they provide. The Department of Mental Health still operates a number of public institutions, including two psychiatric facilities for children, but has closed 13 state-operated facilities or programs since 1990, primarily because the counties have chosen to serve people in their own communities instead of in the state-operated facilities.

The Department of Mental Health provides funding, regulatory oversight, and technical assistance and training to the community mental health boards and their contract agencies. For example, the Department has a Division of Children and Family Services with a number of programs, such as the Permanency Planning Program, the Michigan Interagency Family Preservation Initiative (MIFPI), and the Children's Model II (Medicaid) Waiver Program, that work across the state to achieve departmental goals. The Division also sends out and approves requests for proposals, develops new initiatives, and works with other state departments on projects such as pooling or mixing funds, maximizing use of federal funds to achieve family preservation/support goals, and developing consistent regulations and procedures across departments. The Division also includes a Services Research Unit that conducts evaluations and other types of research on Division programs, including various aspects of the

permanency planning efforts within the state. The Division has had a critically important role in the family preservation and permanency planning successes the state has enjoyed, and continues to play a crucial part in facing the challenges that remain. Figure 1 illustrates the roles played by the state and the counties.

STATE AND COUNTY FUNCTIONS - MICHIGAN

Department of Mental Health
"A Guarantor of Services"

Funds Services
Initiates/Coordinates Statewide Initiatives
Coordinates Statewide Programs (e.g., Children's Model II Waiver)
Develops/Promulgates Policy and Regulations
Provides Technical Assistance/Consultation
Monitors Services
Collaborates with Other State Departments
Manages Federal Funding Streams

Full Management Counties
"Providers of Services"

Plan and Manage Services
Maintain Single Point of Entry into Services
Provide/Contract for Full Range of Services
Encourage Collaboration Between Local Agencies
Collaborate with Local Offices of State Agencies

Figure 1

The rest of this report will focus on services provided by community mental health boards and on the children's initiatives of the Department of Mental Health, and

will not address issues connected with the state-operated programs. First, the report discusses permanency planning as a philosophy. Then, it looks at how the state of Michigan is implementing this philosophy in its developmental disabilities and mental health systems, at the state's efforts to engage in interagency collaboration, at the challenges presented by the cultural diversity within the state, and at the perspectives of biological, foster, and adoptive families.

Permanency Planning Philosophy

A permanency planning approach is based on a philosophy, a way of thinking about and valuing children and families, that provides clear direction when government is involved with children and families. Central to this philosophy is the belief that all children, regardless of disability, belong in families. As a guiding orientation to services for children and youth with developmental disabilities, permanency planning implies the following principles summarized in Figure 2 (Center on Human Policy, 1987a, 1987b).

TYPICAL ASPECTS OF PERMANENCY PLANNING

Family Support Strategies
Family Reunification Efforts
Pursuit of Adoption
Provision of Foster Care
Post-Adoption Supports

Figure 2

Support the Family

Permanency planning is based on the principle that agencies should provide "whatever it takes" to enable children to grow up in families. States that really believe in this principle have flexible, family-centered support programs that can find ways of meeting the diverse and changing needs of families (Taylor, Racino, Knoll, & Lutfiyya, 1987). Some ways states have devised of doing "whatever it takes" include direct cash subsidies to families, voucher programs that can fund a broad range of formal and informal supports needed by families, and programs that are run by family councils. The types of services provided in family-centered programs range widely, depending on the needs and wishes of the family. In the past few years, family activists have advocating for "family driven" programs in which the family, not a case manager or other professional, determines what the family will get (Ellison, Bersani, Blaney, & Freud, 1992).

Encourage Family Reunification

All families cannot at all times maintain their children at home. Crises or other circumstances may require out-of-home placement. Historically, out-of-home placement of persons with developmental disabilities has been viewed as a permanent disposition, and agencies often discouraged a family's involvement with a child after placement.

Permanency planning recognizes the importance of family ties and, therefore, requires substantial effort to ensure ongoing parental contact after placement to

facilitate reunification. A major principle underlying permanency planning is that it is a very rare instance when a child is not better off in his or her natural family. It is, therefore, the responsibility of agencies involved with children and families to use their resources effectively to reunite families whenever feasible.

Pursue Adoption

For children whose ties to their families have been broken, or whose families cannot bring them back home, adoption is the option of choice in permanency planning. Once considered an unrealistic goal for many children, recent experience has demonstrated that adoptive families can be found for children with a range of disabilities (Brown, 1988; Nelson, 1985). Still, many states continue to set up obstacles to adoption. Under the principles of permanency planning, for any child unable to be reunited with his or her biological family, an adoptive family would be the objective of choice. The adoption can be a traditional "closed" adoption, where the two families have no contact and where the biological family does not even know the adoptive family's name or location, or it can be an "open" adoption, in which the child's ties to his or her biological family are maintained and in which there are varying degrees of involvement between the two families. Increasingly, "open" adoptions are viewed as the most appropriate option for many children, especially older ones or children adopted by their foster parents, who may have had extensive contact with the biological parents.

Provide Foster Care

Under a permanency planning philosophy, children who cannot remain at home should be placed in a temporary foster family, not in a congregate care setting such as a group or nursing home, while time and resources are devoted to family reunification efforts. Family reunification efforts can and usually should include contact between both families, so that they and the agencies involved can work together in the interest of the child.

When it is determined that a child cannot return home, but where there are legal or emotional barriers to adoption, permanency planning directs attention to other options to ensure stability for children. These options can include an agreement that a child will remain with a foster family until adulthood rather than being moved from family to family, or "shared parenting," in which a biological and foster family share responsibility for raising a child.

Permanency Planning in Michigan: Children with Developmental Disabilities

This section focuses on how Michigan is implementing the permanency planning philosophy outlined above for children with developmental disabilities, especially those receiving services funded by the Department of Mental Health. Michigan has a number of family support services, including the Family Support Subsidy, for families whose children live with them. Some of these children, and all who live in any type of out-of-home placement, receive service coordination services and are required to have an Individual Plan of Service (ISP). For children not living

with their biological or adoptive families, the ISP must include a written **Permanency Plan**. The Permanency Plan is defined as follows:

> **PERMANENCY PLAN:** means a plan designed to find and make secure a permanent family relationship, be it with the biological or extended family, adoptive family, or foster family, in that order of preference.
>
> The child's client services coordinator (case manager) has primary responsibility for the development of the permanency plan.
>
> 1. The permanency plan shall be developed in coordination with the child's parents, foster parents and referring social worker.
> 2. The priority permanency plan for each child whose parental rights are intact shall be to reunite the child with his/her biological or adoptive family, in the shortest possible time.
> 3. Adoption shall be the permanency of choice for those children who cannot return to their parents' care (or extended family), and whose parents, despite agency support and services, demonstrate an unwillingness or inability to resume custody of the child.
> 4. In those unusual circumstances where neither return home or adoption is considered to be an option, an alternative permanency shall be made for the child including but not limited to a permanent foster family agreement or arrangement.

In the following subsections, we examine in more depth how the state implements the principles of permanency planning.

Family Support in Michigan

Community mental health boards provide services to support families of children with developmental disabilities through what are called "responsible mental health agencies" or "outpatient" agencies. The boards may provide these services directly or through contracts with local agencies. Each community mental health board must designate one mental health agency to serve as a single point of entry for its catchment area, so that families will have just one place to call for services. This agency may then refer families to other agencies or programs for services. In an area such as Wayne County, where Detroit is located, a number of mental health agencies may exist, including those serving Latino, Arab, and other cultural groups. In rural areas, there may be only one agency providing all the family support services. Many of the agencies provide a range of services, such as supported employment programs, adult residential services, adult day treatment programs for people with histories of psychiatric hospitalizations, services to teenage mothers, and substance abuse prevention and intervention for youth, in addition to their family support services. In contrast to other states where some or all of the family support services are provided through parent/family run organizations or boards, those in Michigan are managed by professional staff.

The agency services provided for families of children with developmental disabilities include respite care, clinic services such as counseling, and service coordination. If a family wants just one service, such as respite care or behavioral consultation, they may just receive a referral rather than service coordination by a

family services coordinator. Family services coordinators work with families who need or want more than one service, and help them obtain other services, such as home modification, psychological consultation, counseling, transportation, physical or occupational therapy, and the Family Support Subsidy. These services are funded through a variety of state and local funding sources, and are flexible in their application but have limitations in the amounts of funding or eligibility for services. The Family Support Subsidy, for example, gives a family $230 a month that can be used as they wish, but it is provided only to families whose children are designated as severely mentally impaired, severely multiply impaired, or autistic, by the schools. Services may also be funded by the family's health insurance, and an important role of the family services coordinator is to help families access insurance as well as public funding sources for the services they need.

Family services coordinators also help families to apply for services under the Children's Model II Waiver (CMW II), a Medicaid waiver funded program serving 200 children statewide. Children served by the waiver must meet eligibility criteria that include having intellectual or functional limitations that indicate appropriateness for the ICF/MR level of care. The service coordinators screen families for eligibility for the waiver, complete the paperwork, monitor their progress on the waiting list, process the waiver once it has been granted, and help them to identify providers of the various services for which the waiver will pay. Family services coordinators for children on the waiver also monitor the services provided to families and can terminate the contracts of providers of substandard services. Because they know the families, service

coordinators with the mental health agencies can also obtain extra support for families on the waiting list for the waiver. At times, this is all the family needs, and families have been known to say that things have improved to the point that they no longer need the waiver.

Different community health agencies may offer different services besides those described above. For example, under the "family friend" program, they may provide vouchers so that families can hire friends, neighbors, or family members who do not live with the family to do respite work for the family. Some community health boards do not provide this service because of concerns about liability, while others provide it more readily.

The statistics on numbers of children with developmental disabilities and/or severe emotional disturbances referred to the Permanency Planning Program and placed out of the biological home in Michigan demonstrate dramatically the impact of these efforts to support families. At the end of 1993, only 238 of these children statewide (including some with severe emotional disturbances) were in out-of-home placements funded by the Department of Mental Health. At the same time, thousands of children with developmental disabilities are living with their biological or adoptive families.

From the points of view of agencies and families, however, a number of problems still remain with family support. For example, many families struggle along with very few external supports. Respite care, one of the major services available to families whose child is not served by the waiver, is limited, often undependable, and

often less flexible than families would prefer. Birth families do not receive the support that foster families receive and must often fight for the support they do get. Even when the child's disability is severe, a family may not get the family support subsidy, if the diagnosis given by the school system does not meet the criteria established by the Family Subsidy Program (Knoll, Monschair, Harwood, & Bergeron, 1993). The subsidy may not be enough to cover the child's extra needs, in some cases. Families still find that they must engage in strenuous advocacy and constant coordination to ensure that they and their child receive the treatment they need and deserve.

Also, many more families apply for the Children's Model II Waiver than can be served. While the state is trying to expand the waiver, it has had to develop a priority system for making decisions about which families will be among the 200 receiving waiver services. This means that families get left out or must threaten to place their child in order to get a waiver. Those families who do receive the waiver report other problems, most of which stem from the waiver's emphasis on the child with the disability rather than the whole family. Waiver-funded services are less flexible than services funded through state dollars, but families with children needing extensive services typically cannot get those services with state dollars alone. Even with the waiver, it may be difficult to locate nurses and home health workers who are willing to go into homes, especially in Detroit, and to find occupational and physical therapists to work with children. We spoke with one state official who said,

> There's a price families pay for that, socially or emotionally, and we don't fully understand that. We hear families talk about it... One comment one family

made to me, and it really stuck, was "I've changed from being just a mother to being an employment agency. And now scheduling employees."

Still, the waiver has fulfilled its primary purpose of preventing out-of-home placement. Only one child has been institutionalized since the waiver began, and this was reluctantly done after an enormous amount of work, including consultations by behavior specialists from other states. One other child is in a hospital, and one is in foster care. All the others are still living with their own families.

There are special issues facing families who are very poor or who live in substandard housing sometimes have children with complex medical needs, including needs for medical equipment and care. Whether such a child is born to a family or develops medical problems later, hospital staff are often reluctant to develop a discharge plan for the child to live in the family home. Even when these families want to bring the child home, there may be issues such as a need for backup electrical generating systems, fire hazards, lack of space for equipment and supplies, absence of a telephone, reluctance by home nursing agencies to come into the family's neighborhood, or a lack of confidence in the family's ability to care for the child. If these problems cannot be resolved by the time a child is medically stable, foster care may be used until the housing is improved and/or the family has developed skill in caring for the child. In these instances, the family services coordinator works with the hospital and the family to identify solutions to problems.

Another issue is that poor families are especially likely to say they have been treated badly by medical and other agencies serving them and to have fewer choices

of providers, regardless of the needs of their child. For example, agencies that provide home health care or physical, occupational, or speech therapy often say that they cannot get their employees to go into poor neighborhoods. For families on Medicaid, outpatient care by physicians or therapists is available only through providers who will accept Medicaid.

We have discussed just a few of the many problems the families, agencies, and Department of Mental Health staff are working to resolve. For each system problem we found, we discovered that there are discussions and plans for correcting or easing them. For example, Department of Mental Health staff are discussing the possibility of using the TEFRA (The Equity Fiscal Responsibility Act) option under Medicaid to provide extra services to families who have a child who is designated as needing skilled nursing care (e.g., a child with a tracheotomy). If this is permitted, some children who now receive waiver services, and some families not now on the waiver, could be served by this option instead, and more waiver openings could be created. As another example, the Department of Mental Health is working with other state departments, such as the Departments of Public Health and Social Services, to create a more cohesive system for accessing hourly in-home care so that families will be assessed and served more consistently across departments. Finally, a study of the validity and impact of definitions for the Family Support Subsidy was recently completed and it recommended careful, criteria-based expansion of the subsidy to include other groups of children with severe disabilities (Knoll et al., 1993).

Family Reunification

Even with extensive efforts to support the family, out-of-home placement is sought for some children with developmental disabilities. It is at this point that the permanency planning policies governing residential services take effect. Family reunification is an essential concept in these policies. The family services coordinator's role is to work with the family to determine whether additional supports might prevent placement. If placement is still sought or recommended, the family services coordinator develops a written Permanency Plan. For each child whose parental rights are intact, the priority is to reunite the child with his or her birth or adoptive family as quickly as possible. The Permanency Plan, then, may contain agreements regarding reunification, including specification of changes needed in the family's circumstances so the child can return. The changes specified may become the responsibility of the family, the agency, or both together.

Family reunification efforts mean that placement of the child in foster care is no longer considered a failure. Instead, foster care can be used as part of the reunification process or may be used before families become so exhausted that they are no longer willing to consider bringing the child back home. Also, the foster family can be used to provide respite for the child after the child has returned to the family.

In 1993, the expectation that reunification should occur has become much more explicit. A 1993 guideline disseminated by the Permanency Planning Program states that if reunification does not take place within one year after placement in foster care, consideration should be given to placing the child for adoption. It also suggests that

this should be discussed with the parent(s) in each quarterly review meeting. Some community mental health boards have adopted even more stringent policies, such as that adoption may be sought if reunification has not occurred within six months. Previously, long term foster care (known as permanent foster care, where the child stayed with one family rather than being moved around from foster family to foster family) was an option for families and agencies, but increasingly this is looked upon as undesirable by the state. However, some community mental health boards still readily allow long term voluntary placement in foster care. At the state level, foster care is conceptualized as a temporary placement while needed changes are made for and within the family, in the interest of reunification.

In 1993, the Permanency Planning Program director met with the Michigan Association of Community Mental Health Boards (MACMHB) to develop statewide policy on permanency planning, and especially on reunification. The inconsistency from county to county is not viewed as desirable, but a statewide policy would need to address issues such as flexibility and standardization without penalizing families unnecessarily. Although MACMHB prefers training and technical assistance to policy, a draft policy was developed. The Permanency Planning Director explained the state's position:

> There needs to be an expectation first of all that you never give the family the impression that the child is anybody else's but theirs. In the past we've said we'd take care of the child, and encouraged the separation. We are now continuing to try to turn that around to say, "the decision is in your hands,

you're the legal parent, you need to make a decision." There needs to be a resolution.

He also said that there must be training on how to intervene supportively, on how to confront parents without blaming or taking over for them. Another member of his staff pointed out that the process of reunification can be gradual, that it can start with short visits and extend to weekend and longer visits, with the agreed-upon supports, before the child returns full time.

Family reunification efforts have had results. In 1992, of the 246 children in out-of-home placement, 17 children were reunited with their birth families, and 55 more had a reunification goal. In 1993, 10 families were reunited, and 39 more had a reunification goal.

Foster Care

When a child with developmental disabilities is voluntarily placed in foster care, primary service coordination responsibility for the child passes from the mental health agency to a child placement agency. A child placement agency may provide a variety of services besides child placement, and may or may not have contracts with both the Department of Social Services and the Department of Mental Health. Typically, both agencies work together and with the birth and foster families to facilitate reunification of the family. Also typically, foster and biological families work together in making decisions about the child's care. Across the state, the child placement agencies operating under the auspices of the community mental health boards have done an

excellent job of finding, training and supporting foster families. The rates paid these families vary based on the needs of the child. The small number of children in congregate settings attests to these agencies' success--almost all children with developmental disabilities in Michigan who are not with their biological or adoptive families and who are served by the Department of Mental Health and/or the community mental health boards are living with foster families. In 1992, that meant that of the 246 children in out-of-home placements, 215 were in foster care. Only 31 of the children were living in group homes or residential facilities, and each of these had a permanency plan. In 1993, 192 of the 238 children in placements were in foster care (for both years an undetermined number of these children were in the mental health system. See Figure 3, p. 33).

However, as with the family support and reunification efforts, the achievements of the foster care programs occur through struggle with and ongoing attempts to resolve many challenging problems. For example, we were told that the child placement agencies, for whom the child is the primary client, may view biological families less positively than do the mental health agencies who have worked with them before and through the decision to place the child. The child placement agencies may have less understanding of families' reluctance to take the child back into the home and may push harder for termination of parental rights than the mental health agencies.

Also, in spite of the efforts to achieve a speedy and permanent resolution for children, there are still many children who have lingered in foster care for years. Most

of these children have remained with the same foster family, but have neither been made available for adoption nor returned to the biological family. We met foster families who had children whose biological families were unwilling or unable to bring them back home, but for whom there were apparently no alternative plans being made. At the same time, we also met foster families who had adopted children who had lived with them for years, including parents in their 50s and 60s who had adult children.

For some children, foster care is their permanency plan. In 1993, a permanent foster family agreement existed for 38 of the 192 children in foster care. For others, the community mental health boards have not addressed the issue aggressively. In earlier years, the Permanency Planning Program promoted permanent foster care as an option but has discouraged this option more recently. They found that this became the option of choice in too many instances and feel strongly that the child needs a more stable legal status than that. An outcome of this shift in strategy has meant that families new to the foster care system are confronted early and often about the need to make a decision, while families whose children have been in foster care for some time may not be.

With the counties' shift to the full management system, there is increasing diversity in the way foster families are recompensed and supported. This can contribute to confusion and misinformation on the part of foster families, as well as to competition between counties or agencies for families. Foster families speak to each other, compare notes, and may switch from one agency or county to another if they

feel they will receive a better deal. We met one foster parent who stated that the foster parent and children could move together to another county, and that the new county would hire the parent and assume responsibility for the children. We were later told that this is possible if both counties agree, but would require negotiation. The foster families we met felt they learned more from each other about the available services than from professionals. Typically, they said that another foster family would tell them about something that sounded right for their child and they would tell the agencies that they wanted the service, too.

Many of the foster families felt that they receive more support from the system than biological or adoptive families, and some are hesitant to adopt for fear of losing their services. A foster mother told a story of a parent who adopted her foster child and lost much of her support; when we checked the story with the Permanency Planning Program, we were told that this was a complex situation where the foster/adoptive parent proceeded without the information she needed and fell through some cracks that seasoned professionals would have known how to avoid. However, the situation points up the complexity of the system, and the potential for confusion and distrust that can result when one is dealing with rules and regulations that are difficult to understand and that vary from jurisdiction to jurisdiction. Like biological parents, these parents also complained about the turnover among service coordinators. They all felt that if the service coordinator is not knowledgable, the foster parent is on his or her own.

It is generally true that foster families can receive more services, provided more flexibly, than biological families. They do not have to obtain a Medicaid waiver slot to receive extensive (or even a few hours a day) help in the home and other supports, and they can receive the help they need without following Medicaid regulations. However, we found little evidence that adoptive families receive less support, or less flexible support, than foster families.

Michigan is a culturally diverse state, and has large numbers of people belonging to many different racial or ethnic groups. This presents challenges to child placement agencies. Recruiting enough families of some cultural groups can be difficult, and the agencies have not yet learned how best to find these families. At the same time, there may be pressure not to place children with families of other racial, ethnic, or cultural backgrounds. For example, the National Association of Black Social Workers has taken a strong stand against placement of African-American children in non-African-American families (Berman, 1974; Glidden, 1989), and the state tries to abide by that stand. In some cultures, foster care is an alien concept and is resisted even by families who feel they can no longer keep their children at home. In some cultures, children are cared for with extended family help. Even when the extended family is not available, the family's values may not permit consideration of foster care. Further, because of these values, there may be no other families of that culture willing to foster a child.

The birth families we interviewed (see Appendix) have many feelings and concerns about the foster care system. Some families feel foster care is tenuous.

There is a rising backlash coming from those who feel that group homes are more stable and desirable, and that they permit families to place their children voluntarily and permanently in a way that foster care does not. Some birth families feel distressed by what they perceive as pressure on them, by the implication that if they do not or cannot take their child back into the home within six months to a year after placement, their parental rights will be terminated and the child will be adopted. Other families, however, accept the situation and come to terms with the idea that another family is willing and able to parent their child temporarily or permanently. Some see the child's time in foster care as a time for the rest of the family to regroup, to deal with family problems, and to learn better ways of parenting their child with developmental disabilities.

Another problem is that some children with developmental disabilities come under the jurisdiction of the Department of Social Services rather than voluntarily seeking services through a community mental health program. Social Services holds different values, follows different procedures, and often uses different child placement services than Mental Health. Some of these children have been placed in congregate settings inside and outside of Michigan, and others are in foster care settings operated through Social Services. There are no readily available statistics on these children. The two departments are trying to work collaboratively, but many problems remain. Staff in the mental health system do not have expertise in working through the courts, so collaboration may mean that a child has two service coordinators, one from each system. Mental Health does not see this as desirable. Social Services is a state-

operated system, and when county-level service coordinators from the mental health system, each of whom may belong to a different agency that follows different procedures, try to deal with state employees following state procedures, difficulties can arise for both sides.

Even with these and other problems, the foster care program has provided stable homes for almost all children with developmental disabilities placed out of their homes and into mental health programs since the mid-1980s. The program has been used as the temporary placement of choice, and has allowed the state to avoid the proliferation of congregate care for children so common in many other states. As such, it is a crucial part of implementing the permanency planning philosophy held by state administrators, advocates, and citizens. The problems are not overlooked but have not prohibited the development of a strong foster care program unlike that in any other state developmental disabilities program.

Shared Parenting

There is one collaborative program, funded by a grant from the Skillman Foundation (a Michigan foundation), in which biological and co-parent families make a joint commitment to share the care of a child with developmental disabilities. This program serves up to 15 adolescents who are at risk of placement in Oakland County. The biological family arranges the schedule of care with the co-parent family, and the Oakland County ARC provides service coordination support. The child may spend a maximum of 150 days per year with the co-parent family. We did not visit any families

involved in this arrangement. We did, however, learn of a number of other arrangements that, while they were not called "shared parenting," allowed two families to work out how they would parent a child together. This might be a biological and a foster or adoptive family who have worked out an agreement between them.

Adoption

A decision to pursue adoption is a complex one and may be made by many parties--by the parent(s), by service coordinators and child placement agencies, by other professionals, by the potential adoptive family, and/or by the courts. Some birth families arrive at the decision voluntarily, although possibly under pressure due to the reunification timelines set by some of the community mental health boards. Of the referrals for adoption, 90% are voluntary, and almost all have been open adoptions. A state mental health administrator said, "Of the 80 adoptions we've done, only one has been closed. It's definitely the exception." In an open adoption, the two families know each other and the biological family can maintain its ties with the child. According to Permanency Planning Program and mental health agency staff members, these work very well. Birth families are much more accepting of the idea of adoption when it remains open, which is recommended in almost every case. In a few cases, the decision is made against the wishes of the family. For example, we visited an adoptive family whose child's biological parents were in prison and had severe drug abuse problems. In this case, the issue went to court and the biological family's rights were terminated. During or after the decision-making process, depending on the

circumstances, an adoption agency gets involved. Agencies that specialize in adoption are familiar with the legal and technical requirements for proceeding with an adoption. They are familiar with the courts and can assist the adopting family with each step. When an adopting family has not been identified, they can also recruit such a family for a child. In 1992, 46 children were referred for adoption by the mental health system, and in 1993, 47 were referred for adoption.

Many of the adoptions are by the children's foster families, and thus are by people who already know the child and how to work within the system. Families adopting a child with developmental disabilities are entitled both to an adoption subsidy which mirrors the foster care per diem paid for that child, and to a medical adoption subsidy, if needed or desired. The subsidies can purchase in-home nursing or care, respite services, and other needed services, and can be used more flexibly than can the services available through the Children's Model II Waiver. For example, the in-home worker can clean the house, fix meals, play with the other children in the family, and do other things that help the whole family and not just the child. Adoptive families have not traditionally turned to the mental health agencies for support services, perhaps because they have that resource and are able to broker their own family support. As discussed at the end of this section, this is changing.

Children with developmental disabilities who are eligible for adoption may fall under the jurisdiction of the Department of Social Services, and be unknown to the Department of Mental Health, or they may be served by the community mental health boards. Regardless of which system children are under, children who are freed for

adoption, and for whom there is no identified adoptive family, may be placed on the state's Resource Exchange List. In this case, any adoption agency may find an adoptive family for a child.

Every child who is released for adoption becomes a ward of the Department of Social Services until the adoption occurs. To reduce the confusion that might result for the child and families who have been served until this point by the mental health system, a procedure called "secondary release" is utilized. Under this procedure, if an adoptive family has been identified at the time of termination of parental rights (for example, if the foster family will adopt the child), jurisdiction is given to the Department of Social Services for as little as a few hours or minutes, and is then given back to mental health. The Department of Social Services may have jurisdiction for only as long as it takes to process the termination and secondary release papers in court.

As with the other areas, we discovered that there are many challenges in the pursuit of the alternative of adoption. One is in recruiting families to match the child's racial or cultural identity. For another example, adoption agencies were until recently paid for the preliminary work they did on an adoption, regardless of how long it took or how complex the issue was. Now they are paid a flat amount ($8400) for each adoption. The number of adoptions has risen, but there are concerns about the quality of some of the adoptions. There may have been a rise in the number of multiple adoptions by families--e.g., six or seven children placed with a family, which then comes to need a large number of support services due to the physical, emotional, and financial demands of having so many children with disabilities. Also,

there are indications that an increasing number of families, usually families who received few or no post-adoption services from the adoption agency, have expressed a desire to "give the child back" when the child reached puberty.

To resolve some of these problems, the state applied for and is in its third year of a post-adoption services grant that targets children with emotional disorders primarily, but is serving a few with developmental disabilities as well. Under this program, mental health agency staff members are trained on the issues adoptive families and adoptive children may face. The purpose of the program is to raise awareness that adoptive families may encounter problems and to train counselors and service coordinators in ways of addressing them. In the past, adoptive families rarely came to the mental health agencies unless they were in crisis, partly because there was less understanding of the problems they and their children might face and partly because they were unaware of the services they could receive through these agencies. Now, they are turning more frequently to the mental health agencies.

Permanency Planning in the Mental Health System

Services for children in the mental health system fall under the auspices of the Division of Children and Family Services, which encompasses both mental health and developmental disabilities. We focussed our attention on the Michigan Interagency Family Preservation Initiative (MIFPI) and its efforts to keep children with their families and in their communities. This initiative has the same aims as the services provided through the Permanency Planning Program, but has much less emphasis on adoption

and foster care and uses a different set of terms to describe the services that are developed. Essentially, most of the effort within MIFPI is placed on preserving the family unit and preventing hospitalization of children. When children are at risk of out-of-home placement, they are referred to the Permanency Planning Program, which provides consultation and assistance in developing alternative services for the child.

A number of mental health services focus on in-home, in-community services for children with severe emotional disturbances. For example, a very new program called Wrap Around Services, pioneered in Vermont and Alaska (Burchard & Clark, 1990; Burchard, Burchard, Sevell, & Van Den Berg, 1993), will support children and adolescents, especially those now in out-of-home placements such as hospitals and residential schools, to live with their own or foster families or independently in the community. Other support services for families of children with severe emotional disorders include Children's Assertive Community Treatment (CACT) and other services offered in local mental health centers through the Michigan Interagency Family Preservation Initiative (MIFPI). These services are not available statewide at the present time. In the counties where they are provided, there are families waiting to be served. CACT and MIFPI services are individualized, can work with families in the home or in the mental health center, and help families deal with the other systems (education, juvenile justice, child welfare) with which their children are involved.

The MIFPI project speaks of "family preservation," using a terminology more familiar to mental health and social services professionals to refer to the concepts of family support and family reunification. Where they exist, services to support families

of children with mental health problems are provided under contract, also, but may be located in different agencies than those serving children with developmental disabilities.

MIFPI funds six projects throughout the state, each located within a community health center, that are designed to coordinate services in support of families with children who have emotional disorders. We visited the site of one of the MIFPI projects, which will be described later in this report as an illustration of interagency collaboration at the local level.

Tying it All Together--The Permanency Planning Program

The Department of Mental Health's Permanency Planning Program operates within the Division of Children and Family Services. Its mission is "to ensure that all children in the State of Michigan with special mental health needs have the benefit of permanent membership in a family through the development of community care systems sufficient to sustain these children within their families." The Permanency Planning Program has a Director and four Regional Permanency Planning Coordinators who provide leadership, technical assistance, training and consultation on permanency planning throughout the state. Each Regional Coordinator, for instance, works with the community mental health boards, hospitals, families and other agencies within his or her region to develop solutions for specific children who are at risk of out-of-home or institutional placement. The Program also collects annual statistics on the children in placement, tracking them as they move from one status to

another (see Figure 3). Thus, there is current information on which children each year have reunification or adoption goals and whether those goals have been met, and on which children are working toward transition to adulthood or a less restrictive environment. The Program also provides data on the consultations they do and on the program and staff development projects they have initiated or influenced, such as the special needs adoption and shared parenting projects mentioned earlier.

The Permanency Planning Program is an essential part of the foundation of the state's commitment to permanency planning. Without it, the community health boards, hospitals, and other agencies would fall back on traditional solutions. This was demonstrated a few years ago, when a position freeze meant that one region had no Regional Coordinator. Costs went up due to institutional placements of children, and the community mental health boards, when asked why children were entering facilities, identified the coordinator position as critical. The coordinator who has filled that position since it was restored has worked very hard to ensure that all children live in families.

Interagency Collaboration

This section will focus on Michigan's efforts to develop a collaborative system of service. Historically, outcomes for children and families can be very different, reflecting the varied perspectives of the agencies through which they receive services. With the common goal of permanency planning, however, service agencies across Michigan have begun to coordinate their roles, practices, and funding. The Department of

THE MICHIGAN EXPERIENCE: PERMANENCY PLANNING IN POLICY AND PRACTICE

Children with Developmental Disabilities and Mental Health Problems Out-of-Home 1991-1993

NUMBER OF CHILDREN BY TYPE OF PLACEMENT*

	1991	1992	1993
Foster Care	202	215	192
Group Homes	23	14	12
State Facility	13	9	10
Nursing Home	10	0	1
Residential	8	8	18
	256	246	238

NUMBER OF CHILDREN BY PERMANENCY PLANNING GOALS*

	1991	1992	1993
Family Reunification	49	55	40
Adoption	54	47	63
Permanent Foster Family	47	43	38
Transition to Adulthood	50	44	23
Other (Including Pending)	56	57	74
	256	246	238

PERMANENCY 1991-1993*

	1991	1992	1993
Family Reunification (completed during that year)	24	17	10
Adoption in Progress (not completed during that year)	29	46	47

PERMANENCY PLANNING PROGRAM 1984 - 1993*

Family Reunification:	161
Adoption:	87

Source: Annual Reports of the Permanency Planning Program, State of Michigan

*Includes a small but growing number of children referred by the mental health system, who do not have traditional developmental disabilities. A number of these children have had short or long term residential placements other than foster care. Not all children facing placement in the mental health system are referred to the Permanency Planning Program while every child facing placement in the developmental disabilities system is referred to the program.

Figure 3

Mental Health has worked to facilitate collaboration between the different service systems and agencies to support permanency for children with developmental disabilities. In the process, state administrators have identified important contributions and barriers presented by the various systems and agencies, as well as targeted their efforts toward other children at risk of out-of-home placement. It will be helpful to begin this section with a brief look at the different perspectives in relationship to the permanency planning initiative.

Traditional Roles and Responsibilities

The Department of Mental Health is divided between services for people with developmental disabilities and people with mental or emotional disorders. As explained earlier in this report, Michigan has developed a commitment to providing supports to families of children with developmental disabilities, based on the belief that it is a matter of creating the opportunity and resources a family needs to better care for their child. On the other hand, services for children with emotional disorders have a long tradition of attributing a child's problems to the characteristics of and problems within their families, rather than the lack of opportunities and resources.

Because services through this department are locally controlled, approaches vary from one area to the next, leaving room for flexibility and innovation. The commitment to permanency planning at the state level is beginning to push local mental health services by providing the opportunity for agencies that believe in this approach to reorganize in this direction. The Michigan Interagency Family

Preservation Initiative (MIFPI) projects are not the only examples of agencies moving in the direction of supporting families of children with emotional disorders. One state level administrator has noticed, through the process of reviewing proposals for funding, that local agencies are using language such as "family preservation," "wrap around services," and "assertive community treatment," terms which refer to family centered practices, and are designing services that emphasize keeping children within their own communities.

The Department of Social Services (DSS) has responsibilty for determining if children should be removed from their homes in situations where their safety is in question. If a child is removed, DSS is responsible, under P.L. 96-272, to develop a plan for reunification of the family. Though Michigan has extended the permanency planning philosophy to children with disabilities and emotional disorders, P.L. 96-272 (the Adoption Assistance and Child Welfare Law of 1980) applies only to child and youth agencies (Taylor, Lakin, & Hill, 1987). Therefore, DSS may not be as stringent in implementing permanency planning with children who have disabilities and emotional disorders unless pushed by the mental health system. Many children under DSS jurisdiction live in congregate settings in and out of Michigan, or in long term foster care. The Department of Mental Health is working with DSS to implement permanency planning with children who have disabilities and emotional disorders in situations where it is the primary service agency. In situations where the Department of Mental Health is the primary service agency and legal action such as maintenance

or termination of parental rights is necessary, DSS offers experience and expertise within the court system. Figure 4 depicts services offered by the developmental disabilities, mental health, and social services system.

The Department of Education is another service system that influences a family's capacity to support its child at home. The determination that a child needs a more restrictive educational setting can lead a family or school system to conclude the child also needs a more restrictive living situation. The relationship between education and permanency planning is just beginning to be explored in Michigan.

The Department of Public Health (DPH) offers a history of providing in-home health care and, as the result of deinstitutionalization, it began to extend these services to children with severe disabilities. The Permanency Planning initiative has supported the DPH to continue to build this capacity for children who might otherwise be hospitalized. It is also being challenged to assess and provide services based on the needs of the whole family.

These agencies are addressing many of the problems that arise between them. For example, there are many children with developmental disabilities in foster care or adoption under the Department of Social Services, which contracts with different agencies than does the Department of Mental Health. These agencies often call the agencies funded by the Department of Mental Health, saying they don't have the expertise to serve these children. If the Department of Mental Health took over all

these children, or collaborated with the Department of Social Services in serving them, the service coordination issues alone would be very difficult. However, the agencies are discussing the issues, using both informal and formal processes.

State Level Collaboration

According to one state mental health administrator, all departments are focusing on "children and families, on supporting kids to be at home and strengthening families." Once a month, state directors of the human service agencies including Mental Health, Social Services, Education, and Public Health meet to identify issues and make decisions regarding the allocation and organization of resources toward this purpose. These meetings are guided by "issue papers" submitted by administrators from each of these agencies who also meet regularly. The key issues they are working on are maximizing federal funding, pooling funds, and determining consistent eligibility criteria for services across departments. For example, they are working to make funding streams from Public Health more accessible to families of children with developmental disabilities, providing them with the opportunity for more in-home health care. In another effort, the state is supporting local agencies to come together in determining families' needs in their areas and plans to redirect out-of-home placement money, across departments, for in-home supports.

Working together has resulted in a broad based perspective of permanency planning that involves continuous effort to identify gaps in services across departments. Several initiatives have been developed which lessen the possibility of

PERMANENCY PLANNING SERVICES IN MICHIGAN

Developmental Disabilities
Family Support Subsidy
Family Support Services*
- Respite Care and Sitter Services
- Behavioral Consultation
- Home Modification
- Durable Medical Equipment Purchase
- Other Equipment Purchase
- Nursing Care/Home Health Care
- Short-Term Foster Care
- Skill Training
- Chore Services
- Specialized Transportation Adaptations
- Personal Care Services

Child Placement Services
- Family Reunification
- Foster Care
- Service Coordination

Adoption Services
- Pre-Adoption
- Referral Matching Adoption Process Legal Work
- Post Adoption
- All Family Support Services Above

Mental Health and Social Services
Family Preservation Services
- Children's Assertive Community Treatment
  - -clinical services
  - -social services
  - -respite care
- Families First
- Counseling/Therapy
- Service Coordination

MIFPI
Wrap-Around Services
(support child in or out of the family home, in the community. Includes variety of clinical, educational, living and recreational supports as well as service coordination)

CONGREGATE SERVICES IN MICHIGAN

Developmental Disabilities
- Group Home (one)
- Nursing Home (one child)
- Institution (one child)

Mental Health and Social Services
- State hospitals
- Children's Homes
- Out-of-State Facilities

*Available through Children's Model II Waiver; available also, to a more limited extent, to families not on the Waiver.

Figure 4

children and families falling through the cracks. For example, the need to assess and provide for the needs of the whole family is being extended to adoptive families through the Michigan Post Adoption Services System (MPASS). MIFPI, as mentioned

earlier, is an interagency initiative designed to incorporate the philosophy of permanency planning into services for families of children with emotional disorders. Out of the MIFPI initiative have come plans for a focus group to address the need for human service workers to understand the educational system and rights of people with disabilities and emotional disorders. Other initiatives are in the works, including an effort led by the Department of Education to identify children at risk from the viewpoint of the schools.

In addition to identifying gaps in services, the Department of Mental Health is organizing preventative efforts. Currently several initiatives are directed at prevention. For example, families in which one parent is in prison or is diagnosed with a mental illness are being identified and beginning to recieve services and supports.

Many of the efforts at the state level are proactive. It has, however, been critical that there be safeguards for preventing out-of-home placements at this level. The Permanency Planning Program has sought the collaboration of state departments and agencies in notifying it whenever a referral for out-of-home placment is made for a child with developmental disabilities or emotional disorders. It has been effective in redirecting services in some of these cases, but program staff are concerned that referrals to service agencies not connected at the state level such as nursing homes, private residential agencies and hospitals, and the juvenile justice system, go unreported.

Collaboration at the Local Level

Interagency collaboration at the local level is complex. Some of the agencies through which families receive services are not officially responsible for permanency planning. Those that are connected to state level initiatives differ in the extent to which they see the need or have the flexibility to change their practices.

We met with members of several different types of mental health administered agencies to discuss the opportunities and obstacles they have faced in working towards interagency collaboration. One family support agency we visited is designated by the local Mental Health Board as the "single point of entry," for families with children who have developmental disabilities, into the service system in that area. With responsbility for coordinating services, the agency facilitates bi-monthly meetings for the major service providers with which families come in contact.

Members of the agency described some of the issues they have addressed at these meetings. For example, hospitals are often reluctant to discharge children who need a high degree of medical care to their homes. As a result of working together, the family support agency has realized that if it is able to more quickly get supports such as training and home adaptations to families, hospitals are more cooperative. It has been difficult, however, to gain the cooperation of DSS and many children have gone directly from the hospital to DSS, ending up in foster care. It may not be until after DSS places these children out of the home that social service workers seek assistance from the mental health agencies.

Coordinating efforts with DSS is a priority of the other mental health agencies also. In listening to the issues agencies face, the Director of the Permanency Planning Program developed a clear idea of DSS's role in this effort. Based on its expertise with the court system, he hoped that DSS would retain responsibility for guardianship and continue to work with the courts to either terminate or maintain parental rights. This, however, needs to be guided by the permanency planning policies as implemented through the mental health agencies. Though this is complicated by the fact that DSS contracts with private agencies for foster care and adoption, mental health boards are recruiting and training increasing numbers of placement agencies according to permanency planning policy. In taking over this role, the Permanency Planning Program has struggled to get agencies to implement timelines for family reunification and the termination of parental rights.

In meeting with staff members of the family support agency and representatives of placement agencies, we learned how the pressure to work according to these timelines highlights conflicting priorities between the agencies. For example, placement agencies have a tendency to push for termination of parental rights, while family support agencies want to give families more time to develop the capacity to care for their child.

It is in this struggle that we see the influence of permanency planning in challenging local agencies to understand conflicts that exist among the different agencies and between agency goals and the needs of individual families. The Director of Permanency Planning admitted that it is difficult to implement strict procedures and

timelines. Therefore, the Permanency Planning Program supports agencies to focus on each individual family with an understanding of the biases their services bring to the situation.

Monroe County Community Mental Health Services Board

Monroe County Community Mental Health Board (CMHB) is one of the six sites in Michigan to be awarded a Michigan Interagency Family Preservation Initiative (MIFPI) grant. The agency has a history of supporting families and has identified the challenges it faces in terms of the need for better collaboration between service agencies. It sees MIFPI as an opportunity to learn what it takes for service agencies in their county to work together to prevent out-of-home placement of children at risk. Though they are only in the beginning stages of organizing, their efforts are informative.

The agency has offered support to families whose children are at risk of out-of-home placement through its Family Preservation Services (FPS) since 1990. However, the focus of its efforts has not always been on families. Prior to 1990, it jointly operated a day treatment program with the Intermediate School District (ISD). The idea of the day treatment was to offer a place for children excluded from regular school to receive specialized treatment. Though the children were to return to their regular schools, the Director of FPS explains that they got stuck in day treatment. "Families didn't want to deal with mental health staff at the school or get involved in treatment." The Executive Director of the Monroe County CMHB adds "Teachers and

school environments weren't changing." She was concerned the schools began to view certain children as no longer their responsibility. The agency concluded they needed a new approach, one through which children could still get long term intensive services, but was supportive of the family and a child's right to attend regular school.

As a full management board, Monroe County CMHB was able to divert dollars from the day treatment program and other out-of-home placements to adopt a long term family support approach, commonly referred to as the Children's Assertive Community Treatment Program (CACT) in the mental health field. It is an approach with which they have had much success. Janet and Chris, both mothers of young boys, said they believed their families would not be together today without the supports they received through this program. In addition to counseling for family members at the community mental health center, their families were visited at least once a week by a member of the ACT team. In both situations these visits resulted in trusting, positive relationships between the mothers and the family support workers. Chris and Sue, a social worker, felt they had come a long way in the two years they had worked together. Another mother, Terry, was proud as she talked about the positive ways she had learned to handle problems with her children. She was also pleased that her sons were doing better in school and attributed this to the support of another ACT team member who acted as a liaison between home and school. In addition to these supports, Terry had a number she could call any time of the day or night to talk with one of the members of her team.

Monroe County recognizes their strength in supporting families through this approach and has established the ACT as its direct service contribution to the MIFPI project. It has also identified key roles for other service agencies that are considered critical in this effort including: the Department of Social Services (DSS), Lutheran Child and Family Services, the ISD, Probate Court, and the Department of Public Health (DPH).

Each of the agencies has responsibility for participating in the Case Coordination Team (CCT). Agency directors have designated a management or supervisory staff person to be part of the team which meets weekly to review cases, establish a family as being at risk, and determine which service agency can most appropriately provide in-home supports. The team also provides suggestions to agencies about what resources are available, given a particular family's needs. This process is intended to open all service options to families. The Monroe County MIFPI proposal emphasizes the importance of flexibility in staff roles and a willingness to share resources in achieving this.

In addition to participating in the CCT, each agency has accepted the following roles.

DSS - The agencies have agreed that when a referral is made to their team, the first priority is to determine the child's safety. DSS has accepted responsibility for this role.

Lutheran Social Services - DSS will continue to contract with Lutheran Social Services to provide a short term home based support program called Families First.

Probate Court - Probate Court will redirect out-of-home placement money to provide "intensive probation services."

Intermediate School District - The ISD will see that educational staff are involved in the planning process and cooperate in implementing plans in a way that is "consistent with the recommendations of in-home staff and parental behavioral expectations." In addition, ISD has developed three "crisis intervention teams" with funding redirected from the day treatment program and will offer this service to the schools.

Monroe County Community Mental Health Board - In addition to ACT, Monroe County CMHB will offer Families First, a DSS program providing short-term intensive intervention for families in crisis. It will also provide a "liaison role" with the agencies and take the lead in facilitating the CCT and evaluating the project.

Monroe County Department of Public Health - The Monroe County (DPH) will provide services in cases where there are intense medical or physical needs.

Whatever agency is determined to be the most appropriate primary service provider is responsible for case management. However, in cases where out-of-home placement is being considered there are several safeguards procedures built into the

project. In the case of an initial referral, DSS cannot make the decision that a situation is unsafe without concurrence of the CMHB. The Monroe County CMHB is also looking into the possibility of creating a Placement Council that will include members of all agencies that provide out-of-home placement. The purpose of the Placement Council would be to pool resources, particularly funding, to determine if out-of-home placement is the only option. If a child is moved from the home, the council would designate an agency to provide not only case management, but reunification services.

The developers of the Monroe County MIFPI have focused on the contributions of each agency, but they also anticipate obstacles based on differences in approaches and policies of the agencies involved. As one means of addressing these differences, they have developed an Advisory Council to which CCT will report problems within the system that interfere with providing individualized services. The Advisory Council, made up of each of the directors of the agencies and parents, is responsible for recommending and developing more responsive policies and practices. It is also responsible for identifying and directing future resources to fill gaps in the system and expand those services which are beneficial. A challenge for the project is to gain the cooperation of those service agencies which are not involved in the CCT. For example, though the Department of Education is involved in permanency planning efforts at the state level, schools operate independently and may or may not be cooperative in this effort. The Director of FPS has begun to meet with school administrators to gain their understanding and support.

The Monroe County MIFPI project represents the beginning of permanency planning for children with complex mental health needs through interagency collaboration being implemented at the local level. As the state departments work together to develop policies, pool resources, and create incentives, local agencies are redefining their roles and reorganizing services.

The Families' Perspectives

Our study included many in-depth interviews with family members of children with severe disabilities. It revealed how, even in a state where many diverse services are available, there remains, and maybe always will, a discrepancy between how families think about family-centered and family-determined services and how the human service system can actually provide families with what they feel they need.

Professionals and systems working toward improving family supports have frequently analyzed, written about, and discussed the meaning of support to a family that has a child with a disability. Families also have much to say about what it means to be supported and their perspectives about how they go about getting their family needs met. It is not surprising that even when families feel they have made progress in getting some of the things they need they still feel their struggle and work is on-going.

Families begin with their day-to-day experiences of trying to get their family, and specifically their child with a disability, what is needed. Often times within this process families get to know the system as well or better than many of the professionals who are there to support them. This section highlights some of the perspectives of

families whom we visited in the state of Michigan, most of whom were receiving the Children's Model II waiver. Some had children in foster care, some were adoptive parents, and the others were biological families, including both single parent and two-parent families. They varied in their ethnicity and socio-economic status. Though there were differences in the families' knowledge and professional involvement in acquiring services for their child, they had strong feelings and insights on what support meant for them and their family. Much of this section speaks to the tension parents feel in terms of how life is better for them with services (especially the waiver) and what they feel are their on-going struggles to acquire what they feel they need within the constraints of the social service system.

How Parents See Their Children

First, it is important to establish that many parents look beyond the label that their child has been given and the categories of service that are now available to them. As one mother put it, "She's not a textbook case, she's different, she's very complex." Therefore, specific categories or labels often do not speak to the multitude of the child's needs or to the individuality that the parent sees in his or her child. One single mother was told that her child would be "totally mentally impaired forever." She, however, saw her child differently, saying, "How do you teach someone to see what you have seen him do over four years?" When he cries and cries for hours she gives varying explanations: perhaps he's frustrated because he can't communicate what he

wants, or perhaps there is something going on in his central nervous system that no one can address. She also says, "I have this bright little boy who is manipulative and gets away with murder."

The Family Role: "Everything is a Fight"

Often there is the perception that families are dependent on supports and the professionals who work with them on an on-going basis. Many families, however, see their own work as being a significant part of the support given to their child and their work as advocate as a necessary part of acquiring those supports. While they see particular people as being very helpful and as making a difference in their lives, they see the work of getting what they need as mainly left up to them.

In most cases, families felt that they were in a very vulnerable situation in relation to receiving services. Overall, each of the families that we spent time with felt that they would not be getting what they presently had or needed if they had not spent a lot of their time advocating for their child. While six families explicitly stated that it made a difference to have a worker who knew a lot about the system and was willing to push, they were clear that they played probably the most significant role in getting what their child needed. As one mother said, "I started becoming educated and this is ultimately how we got the kind (of services) we have now." This is often at the expense of being a parent to their child. She continues, " I can't be a mother to my child because I have to fight for what he needs."

They also did not see their efforts as ending but knew that it would be an on-going process. Recapping her early efforts at getting services for her daughter and her need to "hunt down" support people, one mother explained how she knew that those fights would continue for her child who was now over 26: "Why do I have to be the first one over 18 on the waiver and why do I have to be the first one over 26 off the waiver? We're in the process now of trying to get more nursing." Her frustration was like that of other parents whose children had aged out of services, who felt that their efforts must again escalate and they must begin all over with a new set of services.

This often contrasted to how they felt the service system saw their children. As one parent explained, "As long as my daughter draws a breath she is gonna have the need of the system." Yet she felt the system did not acknowledge this long term need. She explained, "If she didn't have the ability to recover, or get better--so eventually there was an end to their services--they weren't gonna provide 'em. By not providing them, they would hasten the end."

In addition a number of the families looked at acquiring the supports and services that their child needed as being as much a part of their work of taking care of their child. "I made some hard decisions over the years," said one single mother, "one of which was to leave work, it was hard but what in the world are you gonna do?" One father talked about it being all right now that he was laid off because of the needs that the family presently had: "I never chose this as a career but it came to me and then you just do it." Each parent talked about the work of caring for his or her child

and family. They saw their daily work as not only caring for their children but also spending a large portion of their time in the work of getting and maintaining services.

Families' Perspectives on the Children's Model II Waiver

The State of Michigan has created the opportunity for 200 families to receive the Children's Model II waiver. The waiver has made a significant difference to the lives of the families who receive it. For example, one family with a child labelled as having severe behavior problems got very limited support in the home prior to the waiver. The child needed someone with him most of the time and this placed a great deal of stress on the family though they were very committed to their son. With the waiver they now receive extended in-home support. The father talked about how difficult it was before and yet how they wanted to keep their son at home:

> We heard of those places and were told to put him away...it's hard to think of giving your child up and not knowing what will happen. He's my son and I've never been a quitter.

Families talk about major events in their and their other children's lives that they could be involved in because of the waiver. As one mother described, "Without the waiver I would not have been able to go to freshman orientation for my daughter...I mean normal things that everybody has the right and wants to do." In another situation, adoptive parents who first provided foster care for a young girl with intensive medical needs explained how their life has changed since receiving the waiver. After

fighting for it a year and a half and having little support from the moment she was their foster child, the mother said,

> Now I have so much. I really do, I feel like I have so much, compared to what I had I feel like I have a very normal life now. I don't have any real gripes about the system now, but my memories are still in place.

There is no doubt that the waiver has made a significant difference to families and has supported families who may otherwise, often against their desire or better judgement, have felt they needed to place their child outside of the home. A problem arises in the number of families that can receive the waiver and how the decisions about who will receive it are made.

Problems Families See With the Waiver

Though life has changed significantly for many families they still raise issues around what must be done to receive the waiver. Often, they feel their integrity is compromised. For example, families that have been on a waiting list can be bumped if another family is deemed to have more significant needs.

In one case, a family waited for approximately three years for the waiver. Then, they were told it would be only a short time but they again didn't receive it. The mother was told, "You didn't insist on out-of-home placement, you didn't have other children and you're not medically depressed." This parent felt she was punished for being, as she said, "functional" and having good "coping skills." Her case manager explained that a family must say: "If need be, they would place the child in foster care.

But if a family says absolutely not, they are deducted points." To this parent it was an insult and contradicted "how I was brought up." She was taught not "to advertise my problems."

This is not an issue of who is to blame. With a limited number of spots it is inevitable that many families who could benefit from the waiver do not receive it and those that do are often made to feel that they must admit they can't handle their situation in order to receive it. For many families this is difficult. They see their need as being great, and that they could not have continued to provide total care for their child without such support, and yet they feel they were punished for the abilities they do have. One mother said,

> As great as Tony's medical needs were, if there would have been a child with medical needs not as great as Tony's but if there would of only been one parent in the home or if the mom had medical problems too, that child would have got the waiver before me.

Parents often feel as though their ability to receive the waiver is based on a sort of competition with each other, and many feel the system plays the role of making them feel guilty. One mother explained:

> This mother, they will say, is worse off than you. I say, "You know what, I feel really sorry for that mother, God help her, because obviously the system isn't, but I'm not gonna let up."

Nursing Care

One of the main concerns for families who received the waiver had to do with the nursing care they received. There is a clash between a family approach and a systems approach to the kind of care needed. Families see the changes their children make, though small and not specifically medical, as very significant to their child's welfare. One mother, who was very upset with the nurse who came into her home and ignored the work she had done with her child over the past years, explained:

> ...she doesn't acknowledge it and then to say to someone, "Oh, he doesn't really understand it does he?" I said in addition to looking at his medical needs, I have to look at his emotional and psychological needs also...I worked for four years to get this child who couldn't communicate with anyone but me to communicate with other people and if someone who is getting paid is gonna come into the home and not even be willing to acknowledge that...

A systems approach would imply that a trained nurse can be sent to any house, that generic training means they will be dealing with a certain list of medical needs which may vary only minimally from family to family. Families felt that for the most part the nursing care did not address the broader needs of the child. In-home nursing care brings the clash of two worlds: the parent as knower and provider for the child clashes with the "trained expert" who comes into the home. Parents often felt unheard and disrespected in relation to being the "expert" on their child and family.

Another issue for families that under the waiver, the nurses and home health workers who come in to help families can only care for the child with the disability.

Parents often do not look at their child's needs as separate from the needs of their family. Instead they think in terms of the needs of the household. For example, if a nurse takes the child with the disability for a walk and the mother has three other young children, it becomes virtually impossible for her to meet other household needs such as grocery shopping during that time. In one case a mother discussed the best nurse she ever had: "Jackie was a good nurse, she really helped me and liked my kids. She would come and take Lena (her child with the disability) and my other kids and take them to the park. Oh, she was really good." Another mother talked about the best nurses that she had: "The nurses I have had care for her, I've done the looking" (she found them herself). I had people that became part of the family." Overall the families wanted people that would address their family needs. Parents felt that nurses who became connected to the family offered the best kind of care. With the number of people coming and going in their lives, they felt the need to form some sort of relationship and intimacy with those people entering their homes.

Retaining good nurses was another problem for some families who felt they were the ones providing the training of the nurses and often times did more than the nurses. In one case, the family and case manager discussed trying to push for the mother to actually receive some of the salary a nurse would get as she was the one doing the work. In all cases where there was nursing involved, the work of getting and keeping good nurses was one of the major challenges that families face.

Respite Care

Respite care is one type of support that is important to families (Knoll, Covert, Osuch, O'Connor, Agosta, & Blaney, 1990). Though available, it was not something that families felt they could count on. Families told stories of planning for respite for their child and then not being able to use it because of staff shortages, illnesses, and the number of places available. Some families were uncomfortable with where respite homes or facilities were located (such as too far away, or in areas of the city where they didn't feel safe, or next to streets where they felt their child could get hurt if she left the house). Some minority families, especially non-English speaking families, felt uncomfortable leaving their child in a place where there was no one who spoke their language or understood their culture.

Family Support Subsidy

Though most of the families we talked with received the family support subsidy, they often questioned the eligibility criteria. The eligibility criteria excluded some families, especially those of children with severe medical needs, from the subsidy. Families of children with severe medical needs felt their needs for the subsidy were as great as those of other families. At the same time, they were torn because they felt they now must struggle to get one of the included labels (severely mentally impaired, severely multiply impaired, or autistic) for their child in order to get the subsidy. Families we talked to felt that children with severe medical needs should receive the subsidy as well.

Foster Care and Adoption

Families have concerns about how the efforts to follow the permanency planning philosophy and guidelines affect their lives as a family. According to one single mother, placing her daughter in foster care was very distressing. In her mind, the placement was temporary, needed only because of the stress of working full-time and taking care of another child who also needed some support. As was previously discussed, when children are placed in foster care there is a review process, and family reunification or permanent placement within a year is encouraged. This parent, however, was very clear about what she needed: "I felt as though the decision for foster care was the best thing for my whole family (temporarily)." She described the review process where every three months she goes through a re-evaluation for a continuation of the placement.

> Every time before I go I get so upset because I'm not ready to bring my daughter home yet. I want to bring her home, she is my daughter, but there are too many other things right now. The biggest thing with this family support is that they have to look at the family not just the child. They said it would be best for her as she gets older to put her up for adoption, but I want her to come home. She is my daughter (beginning to cry).

Though she viewed foster care as temporary, this parent's definition of temporary was different than the system's. She was very happy with the home her daughter lived in, but was distressed over being asked to give her daughter up. She viewed this placement as necessary for her family at the present time but did not want

to give her child up. Though there was conflict, she was able, with the support of her caseworker, to work out an agreement where she wouldn't have to meet as often, and the rules were bent to a degree. This case may be the exception, but it highlights the need for flexibility and respect for what the family has to say about what they want and need.

Another family, who had been foster parents, chose to adopt their daughter who had significant medical needs and had been labelled as a "crack baby" at birth. Their experience with the foster care system was very different than their experience after they adopted. While foster parents they had numerous occasions when their daughter was hospitalized and had significant nursing needs when she returned home. Even in the hospital the family was caught between systems asking who would pay for some nursing care. The mother felt that because her daughter was a foster child with so many needs, no one took a stand:

> I always felt that this (lack of support) was because Jesse was a foster child. It was like they knew she was going nowhere. If Jesse were legally ours--adopted or biologically ours--we knew that there were services out there we tap.

This mother was told not to sign adoption papers until they stipulated that she would also receive nursing care for her daughter but, as she said, "...You don't barter with adoption like that. It's all gonna come out of the same pants pocket in the long run. It's just a different hand reaching in." She felt as though this was a quality issue, that because her daughter had severe medical needs and was not adopted there was less effort being made for her.

In addition, as a foster parent this mother was not able to make the decision of whether or not to keep her child alive. On one occasion she disagreed with the doctors, who didn't want to put her child on a ventilator. The child's biological mother could not be found, and the foster mother insisted she was going to survive and be put on a ventilator. The hospital wrote "NO CODE--Do Not Resuscitate" orders for the child. The only person who could change that was her biological mother, who couldn't be found.

> One of the doctors came in and said, "I understand you're not happy with the decision," and the neurologist said, "It doesn't matter, she's just the foster mother." As a foster parent there was no support...I don't feel like I had any support. I had people listen to me and say, "Gee, that's too bad."

In this case she felt that the people she was dealing with would rather have seen the child die or be placed in custodial care because of the degree of her medical needs.

In addition, this mother said that although the system talks about getting children in foster care to a more permanent placement in 18 months,

> They are not in and out in 18 months unless it's an exception. Don't tell me that, I've had children in my home for 3 years. A child comes into foster care, you can bet they're gonna be there a while.

Other parents feel that foster parents receive more support than biological families. According to one mother, "If they took a third of the services that they offer to foster care families and said to a family (biological) 'we know what you have to deal with'." A sense of contradiction arose for her when she was told that talking about

placement in foster care would make the system realize she was serious about needing more supports:

> Why should I have to say I'll place my child?...He deserves more. I've been the only consistent part of his life. He's had a life of so much pain and suffering. If their goal is to look at what's best for him, how dare they say that foster care is best?

Another issue that was raised is that when biological parents prove to be effective caregivers, especially those who learn how to care for children with severe medical needs, they are sometimes asked to take in foster children to increase the amount of nursing care they would have in the home. One mother describes her feelings after being asked to do this:

> I was like, "ding, ding, God, I could use the money"...I turned around and said, "God, does that make me angry. I need to take a foster care child to support my natural child. I can't get anything for my child, but you're willing to pay me to love someone else's child." I would, but why not take the time and take even a portion of the revenues they are willing to give me and offer it to the natural family?

Respect for Families

For many families who receive services there is also a feeling of being placed in the role of recipient of charity. One parent described,

When you have such a great need and someone gives you a little, you're so appreciative...when I first got nursing in my house,...it was unreal. I had some bad nurses and here I was making them coffee and carrying it to them and fixing their plate...like I'm so glad you're here.

Parents often see themselves as begging and feel they are made to feel guilty for what they are getting. According to them, this is created by how workers deal with them. One parent explained,

Among foster parents we joked about the "Jesus Christ" syndrome. At first they come in and are open to suggestions. They listen to you. They're gonna get out and shake this tree, then they just get so overwhelmed, they cross a line and it's not you and them anymore, it's you against them. They're saying we'll have to be realistic about this. They jump over the line and all of a sudden they're looking down on you. You know, like you're being unrealistic and can't expect...They get you on the guilt and you back away.

She felt that for biological parents the projection of guilt was even stronger than for her because by the standards of society they should be taking care of their children:

But it's not a matter of guilt, you know. It's the need. Unless you get some help..., I remember feeling that I wish Jesse and I would both go to sleep and not wake up. I didn't want her to wake up and me not be there to take care of her...You realize you can't help her and you can't help yourself and either I'm gonna lay down and not wake up or I'm gonna start fighting.

Other Issues for Families and Implications for Providers

While many challenges still exist in supporting families of children with disabilities, families were also very quick to recognize and express appreciation for the support that they were receiving. One parent said, expressing the view of many, "anything they give me is much appreciated or better than what I had. I hope to God there are no cuts."

Potential cuts created major fear for many of the parents we talked with, who wondered whether or not they could depend on the support they were finally receiving. As administrations change, both on the federal level and the state level, they saw support as being very tenuous. Families look at needs as on-going and the support as something that they build into the fabric of their daily lives, where such considerations are seldom made with systems. There is always a sense in families that they could lose what they fought for and are now receiving.

There is no doubt that the provision of the Medicaid waiver as well as the other benefits offered by the state of Michigan were of value to families, but this did not mean that families saw their fight as being over. In fact, they did not feel that they were dependent on such entitlements but rather they saw them as at least a brief reprieve from their efforts to secure some help for their family.

The tension lies in the fact that first of all, the system will never be able to provide all that families need. In recognizing this, however, it is important to look at the many factors that are involved in supporting families, some of which require no extra money. First, it is important to recognize the work that families do on a daily basis to

get what they need, not only for their child with a disability but for their family. Second, we must try harder to listen to and respect the expertise that families have about their children and their lives. While much lip service has been given to the language of respecting parents and really listening to them, we as professionals still appear afraid to trust them. Parents in Michigan, as is true of parents all over the country, ask nothing more but certainly nothing less.

Conclusion

The State of Michigan is to be commended for its ongoing commitment to the goal of ensuring that all children with disabilities will grow up in families. While this study identified many problems and concerns, the fact remains that children with disabilities in Michigan have a better chance than anywhere else in the country of having a stable and permanent family to live in, and of having much of the support they need. To make this goal a reality, people all over the state, from state officials to parents, have had to work very hard on behalf of individual children as well as at a systems level.

Other states are now beginning to learn from the Michigan experience and to implement a permanency planning philosophy for children with developmental and/or emotional disabilities. In 1991, Steven J. Taylor wrote, "Michigan...is teaching the country many lessons. At the rate it is progressing, it will have many more to teach." (Taylor, 1991). This statement still rings true. The lessons now have to do with interagency collaboration, addressing poverty, emphasizing permanency planning for

children with severe emotional disorders, refining and expanding the Family Support Subsidy, addressing the discrepancy between a good system and the fact that families continue to struggle, and identifying new sources of funding, to name a few. Most important, however, is the lesson that all strategies must relate back to the basic goal, the goal of ensuring permanent family homes for all children.

Appendix: Methods

The Center on Human Policy has examined Michigan's permanency planning approach since 1985 (Taylor, Racino, Knoll, & Lutfiyya, 1987; Taylor, 1991). Late in 1992, we heard about new programs, including the work to apply the permanency planning philosophy to children and families involved in the mental health system. We decided to conduct an in-depth look at the programs, and formed a research group to investigate and write about how Michigan has developed and expanded permanency planning over the years. Three of us (the first three authors) visited Michigan, spending most of our time interviewing and observing community mental health agencies, child placement agencies, Division of Children and Family Services staff members, the Director of the Department of Mental Health, multipurpose agencies serving specific cultural groups, and birth and foster families. Tapes made of most interviews were transcribed. Other observations were recorded using portable computers, usually very soon after the encounter or interview.

After the interviews were transcribed, each researcher read everything that had been transcribed and met to generate themes that emerged within and across interviews. We developed an outline for the analysis and divided up the writing tasks. When the first draft was completed, it was sent to key administrators in Michigan for suggestions regarding accuracy of details. The final draft was completed after their review.

References

Berman, C. (1974). We take this child: A candid look at modern adoption. Garden City, NY: Doubleday.

Brown, E. (1988). Recruiting adoptive parents for children with developmental disabilities. Child Welfare, LXVII(2), 123-135.

Burchard, J. D., & Clarke, R. T. (1990). The role of individualized care in a service delivery system for children and adults with severely maladjusted behavior. Journal of Mental Health Administration, 17(1), 48-60.

Burchard, J. D., Burchard, S. N., Sewell, R., & VanDenBerg, J. (1993, August). One kid at a time: Evaluative case studies and description of the Alaska Youth Initiative Demonstration Project. Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center.

Center on Human Policy. (1987a). A statement in support of families and their children. Syracuse, NY: Author.

Center on Human Policy. (1987b). Families for all children. Syracuse, NY: Author.

Ellison, M. L., Bersani, H., Blaney, B., & Freud, E. (1992). Family empowerment: Four case studies. In V. J. Bradley, J. Knoll, & J. M. Agosta (Eds.), Emerging issues in family support. Washington, DC: American Association on Mental Retardation.

Glidden, L. M. (1989). Parents for children, children for parents: The adoption alternative. Washington, DC: American Association on Mental Retardation.

Knoll, J., Covert, S., Osuch, R., O'Connor, S., Agosta, J., & Blaney, B. (1990). Family support services in the United States: An end of decade status report. Cambridge, MA: Human Services Research Institute.

Knoll, J., Monschau, L., Harwood, T., & Bergeron, S. (1993). A study of the validity and impact of proposed eligibility definitions for the Family Support Subsidy. Detroit: Developmental Disabilities Institute.

Nelson, K. A. (1985). On the frontier of adoption: A study of special-needs adoptive families. New York: Child Welfare League of America.

Taylor, S. J. (1991). Toward families for all children. In S. J. Taylor, R. Bogdan, & J. A. Racino (Eds.), Life in the community: Case studies of organization supporting people with disabilities (pp. 19-33). Baltimore: Paul H. Brookes Publishing Co.

Taylor, S. J., Lakin, K. C., & Hill, B. K. (1989). Permanency planning for children and youth: Out-of-home placement decisions. Exceptional Children, 55(6), 541-549.

Taylor, S. J., & Newman, P. (1993). Permanency planning in policy and practice: The Michigan experience. TASH Newsletter, (4), pp. 10-11.

Taylor, S. J., Racino, J. A., Knoll, J., & Lutfiyya, Z. (1987). Down home: Community integration for people with the most severe disabilities. In S. J. Taylor, D. Biklen, & J. Knoll (Eds.), Community integration for people with severe disabilities (pp. 36-63). New York: Teachers College Press.

Taylor, S. J., Racino, J. A., Knoll, J. A., & Lutfiyya, Z. (1987). The nonrestrictive environment: On community integration for people with the most severe disabilities. Syracuse, NY: Human Policy Press.

Taylor, S. J., Racino, J. A., Walker, P., Lutfiyya, Z. M., & Shoultz, B. (1992). Permanency planning for children with developmental disabilities in Pennsylvania: The lessons of Project STAR. Syracuse, NY: Center on Human Policy, Syracuse University.